



Improving Sickle Cell Treatment and Outcomes

Transforming Health Care Delivery and Provider Capacity

Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada,
New Mexico, Oregon, Utah, Washington, Wyoming

Sickle Cell Treatment Demonstration Program Grant: <http://pacificscd.org/>

California Sickle Cell State Action Planning Initiative

Vision

Sickle Cell Equity California
#SaveSickleCellLives

Mission

Build an effective statewide coalition of key stakeholders to educate, equip, and empower Californians about sickle cell disease, sickle cell trait, and other blood disorders.

Who: A coalition of key stakeholders, under the leadership of the Pacific Sickle Cell Regional Collaborative, has come together to create California's first ever Sickle Cell Statewide Action Plan.

Why: The average life expectancy for individuals with sickle cell disease (SCD) in California is well below the U.S. general and African American populations. It is also below the average compared with SCD populations in other states. There are not enough knowledgeable providers to adequately care for youth and adults with SCD, leading to increased emergency room visits and hospital admissions, and decreased quality of life. There is a lack of community awareness about SCD and sickle cell trait (SCT) and a lack of adequate follow-up for families for whom SCT is identified through newborn screening. As a group, people with SCD experience worse health outcomes compared to other diseases and have access to fewer health resources. This lack of equity is a health disparity.

Our Response: Individuals with SCD, family members, experts, community based organizations, advocates, and other partners met on January 27, 2018 as we began the detailed process of creating the California Sickle Cell State Action Plan. We are identifying public health priorities and key implementation agencies needed to improve the health of Californians affected by SCD and SCT. We envision the Action Plan to be a road map that will transform healthcare delivery, access to and cost effectiveness of care for Californians with SCD. The Executive Summary was completed after extensive stakeholder input in December 2018. Our goal is for providers, agencies and the community to collaboratively implement the plan, which will articulate needed steps to ensure that individuals with SCD receive comprehensive, patient-centered, coordinated, accessible, safe and high quality care, no matter where they live or seek care in California. For SCT, we envision that the plan will outline steps for agencies to take to promote a model for SCT follow-up where individuals have access to information and counseling to make informed decisions about their reproductive health and about the unique circumstances in which SCT may have an impact on their overall health status.

Join us! We welcome partners and supporters. We have established three workgroups – Outreach/Advocacy/Community Awareness, Policy and Clinical – a Steering Committee and a Writing Committee to craft the California Sickle Cell State Action Plan. Please join one of the workgroups, and/or be sure to add your voice to the development of our California Sickle Cell State Action Plan by responding to occasional surveys. Again, the Action Plan will serve as a roadmap for improvement to educate, involve and motivate decision makers about SCD and SCT.

For more information, contact

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You can also visit <https://ca-actionplan.pacificscd.org/> for more information and for updates on the California Sickle Cell State Action Plan as it progresses.